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# Out of the shadows: non-communicable diseases and palliative care in Africa

R A Powell,<sup>1</sup> Z Ali,<sup>2</sup> E Luyirika,<sup>3</sup> R Harding,<sup>4</sup> L Radbruch,<sup>5</sup>  
F N Mwangi-Powell<sup>6</sup>

<sup>1</sup>Global Health Researcher,  
Nairobi, Kenya

<sup>2</sup>Kenya Hospice and Palliative  
Care Association, Nairobi, Kenya

<sup>3</sup>African Palliative Care  
Association, Kampala, Uganda

<sup>4</sup>King's College London Cicely  
Saunders Institute, London, UK

<sup>5</sup>Department of Palliative  
Medicine, University of Bonn,  
University Hospital Bonn,  
Malteser Hospital Bonn/Rhein-  
Sieg, Bonn, Germany

<sup>6</sup>University Research Company,  
Nairobi, Kenya

## Correspondence to

RA Powell, Global Health  
Researcher, P.O. Box 459-  
00621, Village Market,  
Nairobi, Kenya;  
[richard2powell@yahoo.co.uk](mailto:richard2powell@yahoo.co.uk)

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## ABSTRACT

Non-communicable diseases (NCDs) in Africa have been comparatively neglected, partly due to donor-driven funding priorities. This is despite NCDs being the principal cause of mortality globally, with the majority incidence occurring in low-income and middle-income nations. Most of the patients with NCDs will suffer from pain, breathlessness and other physical symptoms, or need support with psychosocial or spiritual problems. Reflecting regional disease prevalence, late-stage clinical presentation, limited funding and restricted access to curative therapies, palliative care need in Africa is significantly high. Although palliative care provision has advanced significantly on the continent in the past decade, much of this development was driven by services for adult HIV patients. However, recent international and regional political declarations and commitments constitute a new global NCD agenda that calls for the integration of palliative care into the NCD response. This could be achieved under a chronic care model of service provision in partnership with other clinical providers in an integrated care continuum spanning prevention, early detection, diagnosis, treatment, survivorship and the end of life. Four important challenges have to be addressed if palliative care is to contribute meaningfully to this NCD agenda: (i) existing variation in the ability of countries to deal with NCDs per se; (ii) ensuring clinical partners are integrated effectively with palliative care; (iii) agreeing implementation is linked to relevant national-level and patient-level metrics; and (iv) underpinning palliative care and NCD care with a rigorous and locally relevant evidence base demonstrating appropriate, feasible and effective care.

## OUT OF THE SHADOWS: NCDs AND PALLIATIVE CARE IN AFRICA

"For too many years we have focused almost exclusively on the threat and impact of HIV. We have failed to consider the burden of non-communicable diseases."

An attending doctor sitting by the bedside of an ailing patient with diabetes in a Kenyan public hospital

Non-communicable diseases (NCDs) on the African continent have been comparatively neglected. This is partly related to donor-driven funding priorities on palliative care for HIV/AIDS.<sup>1</sup> NCDs are the principal cause of mortality globally, accounting for 36 million deaths in 2008 (63% of total fatalities), with four-fifths occurring in low-income and middle-income nations.<sup>2</sup> Unlike in other regions, the proportion of annual mortality caused by NCDs in Africa is less than that of communicable diseases, especially HIV/AIDS (table 1).

Diabetes and cancer are, however, increasingly significant public health problems on the continent. Diabetes cases in sub-Saharan Africa are expected to increase from 4.8% prevalence (19.8 million) in 2013 to 5.3% (41.5 million) in 2035.<sup>4</sup> In 2012, there were 645 000 new cancer cases and 456 000 cancer-related deaths in Africa, projected to nearly double (1.28 million new cases and 970 000 deaths) by 2030.<sup>5 6</sup> Specific cancer-related problems in African countries include the high percentage related to infection (36%, twice the global average),<sup>6</sup> late patient presentation to

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## Feature

**Table 1** Non-communicable disease (NCD) deaths in sample African countries

Country	2014 population (millions)	Total NCD deaths (000 s)	NCDs as per cent of all deaths	Probability of dying from an NCD*	Communicable, maternal, perinatal and nutritional conditions as per cent of all deaths
Kenya	43.2	369	27	18%	64
Malawi	15.9	151	28	19%	65
South Africa	52.4	608	43	27%	48
Uganda	36.3	353	27	21%	60

Source: Adapted from the WHO.<sup>3</sup>

\*Between 30 and 70 years old from the four main NCDs (ie, cardiovascular diseases, cancers, chronic respiratory diseases and diabetes).

clinical services and limited access to essential analgesics because of legal and regulatory restrictions, inadequate training of healthcare providers, procurement difficulties and weak health systems.<sup>7 8</sup> By 2030, mortality due to NCDs will be the most common cause of death in developing countries,<sup>9</sup> caused by ageing populations, the adoption of riskier lifestyles, and deficient diagnostic, preventive and curative treatment services. By 2020, the largest increases in NCD fatalities will occur in Africa.<sup>10</sup>

Most patients with NCDs will suffer from pain, breathlessness and other physical symptoms or need support with psychosocial or spiritual problems.<sup>11</sup> Reflecting the above factors, palliative care need in Africa is significantly high. For example, among Ugandan hospital inpatients, Lewington *et al*<sup>12</sup> found that 122/267 (46%) had an active life-limiting disease with NCD diagnoses including: cancer (22/122, 18%), heart failure (11/122, 9%), renal failure (11/122, 9%), liver failure (3/122, 2%) and chronic obstructive pulmonary disease (1/122, 1%).

Harding *et al*'s<sup>13</sup> study of symptom prevalence and burden among patients with advanced cancer receiving palliative care in two African countries found a mean of 18 symptoms, with the five most prevalent being pain (87.5%), lack of energy (77.7%), feeling sad (75.9%), feeling drowsy (72.3%) and worrying (69.6%). Another recent study by Harding *et al*<sup>14</sup> measured 3-day period intensity of multiple problems among patients with advanced cancer in Kenya and Uganda. It found that patients were most severely affected by pain, a lack of information to plan for the future, and that need increased as function declined, suggesting the importance of home-based care models with adequate family support.

Palliative care provision on the continent has advanced significantly in the past decade.<sup>15</sup> In 2011, the World Palliative Care Alliance (2011) reported that nine countries progressed from no known activity/capacity building (groups 1/2) to isolated provision (group 3a), while four countries moved from group 3 to 4a (preliminary integration into mainstream service provision), with Uganda in group 4b (advanced integration into mainstream service provision).<sup>16</sup> Progress has been less impressive with paediatric palliative care services, with 43 of 53 African countries ranked in

group 1 (no known activities), and only 1 in group 4 (provision reaching mainstream).<sup>17</sup>

Much of this service development has been for adult HIV patients under funding from the President's Emergency Plan for AIDS Relief. However, recent international and regional political declarations and commitments constitute a new global agenda. Further to the 2011 United Nations' High-level General Assembly Meeting's declaration on the Prevention and Control of Non-Communicable Diseases,<sup>18</sup> in 2013 the African Union (AU) declared commitment to the NCD agenda at its Sixth Conference of AU Ministers of Health in Ethiopia. This was recently echoed by adoption of the Luanda Declaration in Angola by African Ministers of Health in 2014, pledging to commit to concerted multisectoral efforts to prevent the common risks related to NCDs.<sup>19</sup> Currently, too, there are calls to include palliative care in the Sustainable Development Goals' global health agenda.<sup>20</sup>

On the basis of experiences in delivering care to patients with chronic HIV infection and also patients with cancer, an opportunity exists to contribute to this global agenda by providing palliative care for patients with NCDs generally. This could be achieved under a chronic care model of service provision in partnership with other clinical providers in an integrated care continuum spanning prevention, early detection, diagnosis, treatment, survivorship and the end of life. These services offered should be holistic in nature, addressing the varying needs of patients with NCDs, including non-physical symptoms and distress (eg, spiritual concerns) and configured to meet the specific challenges of chronic conditions. These include potential comorbidities (requiring clear practice guidelines and effective coordination between services) and training in self-managed care among patients, as well as extended interactions with the healthcare system. This approach will require a transformation in the approach of many palliative care services, from one that is reactive to the symptom burden of the patient, to one that is proactive and focused on maintaining health and performance status as well.

This is no small goal. Despite the need to integrate it within national public health systems, palliative care

on the continent remains heavily reliant on non-governmental, community-based and home-based care models.<sup>21</sup> Acknowledging that implementation of palliative care in mainstream healthcare services will take time to be realised, existing service delivery systems need to begin to work effectively and in an integrated way in order to optimise their impact on patients with NCD under the chronic care service model.

Part of this work will entail sensitising and training front-line staff to the needs of patients and caregivers with different diseases and disease trajectories, including long-term (for renal, lung or cardiac failure) and rapid decline trajectories (eg, for cancer). Additional training will be required for illnesses—such as renal or heart failure or age-related degenerative diseases—more common in economically developed nations. Moreover, palliative care services will need to resolve how they can manage an ongoing relationship with patients with chronic, non-malignant NCDs requiring much longer engagement periods. One option for consideration is the use of mHealth technology platforms which have been found useful in engaging patients and their families (eg, via SMS text messages to encourage medication adherence, follow-up appointments, healthy behaviours and partner notification),<sup>22 23</sup> as well as in providing health information to front-line health workers operating in remote areas.<sup>24</sup> Fluctuations over time in the NCDs' trajectories also lend themselves to a 'brief' model of palliative care, where services provide assistance on a time-limited, periodic basis as patient need dictates.

However, four important challenges need to be addressed if palliative care is to contribute meaningfully to this NCD agenda. First, variation exists in the ability of countries to deal with NCDs per se, with some reporting national responsible agencies but most lacking even basic monitoring systems, for example, national, population-based cancer registries to determine disease prevalence.<sup>25 26</sup> Palliative care advocates must campaign in conjunction with partners working with chronic care patient populations for these monitoring and reporting systems and other prerequisites to their effective detection, tracking and management.

Second, there is a need to ensure that palliative care is integrated with the growing NCD agenda. Services such as cardiology, renal care and respiratory medicine should be enhanced by basic palliative care training for their staff (eg, including effective pain and symptom management, patient communication and decision-making, eg, on treatment withdrawal) and by developing clear referral protocols in palliative care centres for those with complex palliative care problems.

Third, its implementation across Africa must be linked to a relevant measurement framework. The WHO has identified access to palliative care assessed by morphine-equivalent consumption of strong opioid analgesics (excluding methadone) per death from

cancer as a global monitoring indicator for palliative care in its *Action Plan for the Global Strategy for the Prevention and Control of Non-communicable Diseases*.<sup>27</sup> However, it is both an imperfect proxy for palliative care development generally<sup>28</sup> and more relevant to the end-stage of the disease rather than long-term provision of palliative care for NCDs generally from the point of diagnosis. Therefore, while reporting of a morphine-equivalent consumption per capita is already required of national governments by the International Narcotics Control Board, using it as a single global indicator for palliative care is problematic.<sup>20</sup>

In the absence of an agreed global indicator, there is merit in the adoption of national-level and patient-level metrics. At the national level, this could entail mapping indicators of palliative care progress, such as those advocated by the Latin American Palliative Care Association (see [table 2](#)).<sup>29</sup>

However, to ensure that advances in palliative care nationally are underpinned by effective clinical care provision, patient-level metrics using validated outcome measures (eg, the APCA African Palliative Outcome Scale (POS)) should also be routinely used. Indeed, its use could facilitate the engagement of both the patient and their family members with the healthcare system, with the linkage maintained via mHealth technology. While the APCA African POS has been used among patients with HIV and cancer diagnoses, it needs to be validated among other NCD clinical groups.

Fourth, palliative and NCD care must be underpinned by rigorous and locally relevant research demonstrating appropriate, feasible and effective care,<sup>30 31</sup> as an integral part of the public health palliative care strategy.<sup>32</sup>

**Table 2** National-level palliative care mapping indicators

Domains	Indicator
Policy	1. Existence of a current national palliative care plan/programme
Education	2. Proportion of medical schools which include palliative care education in undergraduate curricula
	3. Proportion of nursing schools which include palliative care education in undergraduate curricula
	4. Number of specialised palliative care educational programmes for physicians, accredited by the national competent authority
	5. Inclusion of palliative care in the list of services provided in the primary care level
Service provision	6. Number of palliative care services per million inhabitants
	7. Number of physicians working in palliative care per million inhabitants
	8. Consumption of strong opioids per cancer deaths
Medications	9. Consumption of strong opioids per capita
	10. Number of pharmaceutical establishments that dispense strong opioids per million inhabitants

NCDs in Africa have finally appeared from the shadows of the AIDS epidemic. Indeed, the 67th World Health Assembly's adoption of the resolution on strengthening palliative care as a component of integrated treatment throughout the life course, for diseases including advanced NCDs,<sup>33</sup> means that there is a growing regional impetus for, and expectation of, palliative care services on the continent.

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R A Powell, Z Ali, E Luyirika, R Harding, L Radbruch and F N Mwangi-Powell

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